

The Nurse's Role in Rehabilitation of the Child With Rheumatic Fever

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INCRIMINATION of group A streptococcal infection as a precursor of rheumatic fever, the advent of antibiotics, improved diagnostic tools, and better living conditions have helped reduce the incidence of rheumatic fever and its sequela, rheumatic heart disease (1).

Secondary prevention, or the prevention of recurrences of rheumatic fever, is essential in reducing the risk of rheumatic heart disease. Continuing antibiotic prophylaxis against streptococcal infection has been a proved and effective procedure for this purpose for many years.

More recently, primary preventive measures have been facilitated. However, there is no cause for complacency. Rheumatic fever and rheumatic heart disease still blight the lives of thousands of American children and adults.

Because rheumatic fever reporting is not required in all States, national incidence and prevalence figures are necessarily incomplete. Nevertheless, the National Office of Vital Statistics of the Public Health Service reported 10,470 cases of rheumatic fever during 1961 in the United States, and there are still more than 18,000 deaths a year from rheumatic heart dis-

ease and rheumatic fever. Although there is great need for more complete morbidity reporting of rheumatic fever, the available statistics are an impressive indication that American medicine and public health are still confronted with prevention, casefinding, and rehabilitation.

The fact that rheumatic fever is essentially a disease of childhood compounds its seriousness, for it can cause lifelong disability. The rheumatic child is often father to the man with disabling rheumatic heart disease. Furthermore, the high recurrence risk of the disease places it in a category in which prevention is an intrinsic part of treatment and rehabilitation.

This paper describes the nurse's role in rehabilitation of the child with rheumatic fever or with its frequent result, rheumatic heart disease.

Rehabilitation is often called the third phase of medicine, diagnosis and treatment being the first two phases. This third phase does not follow the first two in sequence. Rather, it is simultaneous with them. Rehabilitation begins with diagnosis and continues through treatment seeking to achieve the greatest physical and emotional restoration possible for each patient.

Many persons participate in the rehabilitative process: the physician, nurse, mental hygienist, social worker, nutritionist, vocational counselor, clergyman, physical therapist, occupational therapist, the patient's family, and most important, the patient himself.

Of all these, the nurse is perhaps the one person in the community who sees the patient in every stage of his illness, from diagnosis through recovery and adjustment to any residual disability. She may be a school nurse, hos-

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pital nurse, office nurse, or public health nurse, or indeed, "she" may be several nurses. It is the nurse's acceptance of rehabilitation as part of good nursing care that helps to imbue both the patient and his family with the firm belief that physical and emotional restoration is not only possible but a natural and unquestioned goal of treatment.

As in all patients with long-term conditions, family attitudes play a leading role in rehabilitation of the child with rheumatic fever. Fears and worries are often unintentionally communicated to the child. Overprotection may result in unfavorable emotional results that may outlast a physical condition for which science may have an answer.

The Rheumatic Child

Rheumatic fever has its highest incidence among children between the ages of 5 and 15, the 10 years that encompass the beginning of independence, of adjustments to group situations in school and at play and to the academic situation.

At best, rheumatic fever imposes long bed rest and restriction of activity for weeks or months; at worst, it leads to crippling heart damage. Either, during the crucial growing-up years, can be catastrophic for many children, unpleasant and frustrating for most.

How may the nurse help these children? Regardless of her place of practice (doctor's office, health agency, Visiting Nurse Association, or school), the nurse is an informed professional who must be able to interpret the disease, its effects, and treatment to the child and to his family. Whether diagnosis is made in the physician's office or in a clinic, she is often called upon to explain the physician's orders, to answer anxious questions, and help the child and his family to cope with the myriad problems of long-term disease.

Because of the danger of recurrence, the nurse must be able to state simply the reasons for continuing prophylaxis and to explain adequately the signs and symptoms of the precursor of rheumatic fever—streptococcus infection. These include sore throat, aching joints, elevated temperature, alone or in combination. Loss of weight, easy fatigability, sweating,

marked pallor, chest or abdominal pain, headache, or vomiting should also be reported to the attending physician.

If the child must be hospitalized, a frank discussion of why it is best and what will happen during the experience can help ease the pangs of separation and the fears of both family and child. Frequently the nurse may help to resolve personal or financial problems through an informed referral to a social worker or to a community welfare agency.

The hospitalized child is largely dependent on the clinical nurse not only to care for him but to imbue him and his family with the hopeful attitudes and incentives so necessary for rehabilitation. Indeed, the nurse can start the whole process of rehabilitation and pave the way for the years ahead. She may also make referrals for social work and for help from various community agencies. She can be of invaluable aid to the family in their planning for home care, as necessary, following discharge.

For children who will need extended convalescent care, the transition from hospital to home is often facilitated by a public health nurse or visiting nurse. The nurse will, of course, receive a report from the physician concerning the patient's diagnosis, any special medical problems, and the patient's rehabilitation requirements, along with orders for medical treatment in the home. Ideally, she will visit the patient while he is still in the hospital and consult with the physician and the hospital nursing team. This will enable her to understand the course of the illness and the rehabilitation measures already initiated.

If homebound teaching is indicated, the public health nurse is in a position to make a referral that will enable the child to continue his education. On the other hand, if the community does not offer such a program, the school nurse can often help teachers to arrange for sending class work to the home. For example, in some communities school nurses have worked out a plan with the local telephone company for telephone communication to the classroom. Some States have laws which provide homebound teaching if a child is out of school for 6 weeks or more.

Most children with heart disease are spared the embarrassment of looking different, but

lowered physical endurance may make them feel different.

What about the future of these children, particularly those with valvular damage? If the nurse gets to know the child early in the course of his illness, she can begin to prepare him to think about modified types of activity rather than competitive sports and heavy manual labor. She may refer him to a vocational guidance counselor or a vocational rehabilitation facility for guidance. This early approach is better than waiting until the child reaches adolescence when his plans may be suddenly upset. It is often up to the public health nurse, who has established years of rapport with a young patient, to assure him that he can participate in society with modification of certain activities.

Prophylaxis

One of the most trying aspects of rheumatic fever is the long-term therapy currently recommended to prevent recurrence. Physicians differ as to the kind and term of prophylaxis needed. Whether or not a child has carditis, some physicians may recommend oral penicillin for life or for several years, while others will prescribe penicillin by monthly injection for varying periods. For a child, any of these measures may appear to be discouraging long-term sentences, particularly when he feels well. The public health nurse, visiting nurse, or school nurse is in a position to help motivate the patient to continue prophylaxis.

If medication prescribed is oral, she can help set up a schedule, a convenient, easily remembered time for taking the pill. She can stress the importance of medication as a daily habit, like brushing the teeth, in preventing recurrences of rheumatic fever and subsequent heart damage. To allay undue fears of occasional delinquency, she can also explain that failure to take pills for a day or two is unlikely to result in recurrence in view of the incubation period of several days for the streptococcal infection. However, these fears obviously do not disturb most children who feel well. The problem is, instead, the high rate of delinquency in oral prophylaxis, particularly during the years of

adolescence when pill-taking may become just another parental dictum to be flouted.

One study of rheumatic fever patients at the Grace-New Haven Hospital, New Haven, Conn., showed that a sharp rise in delinquency in taking penicillin began at the age of 13, the peak delinquency rate (45 percent) appearing at the age of 17—a time when the adolescent is feeling a growing desire for independence (2). This study was based on information supplied by dispensers of penicillin in the community and on interviews with all patients known to the children's cardiac clinics at Yale University. The delinquency rate was found to be related more to the age of the patient when he started prophylaxis than to the length of the treatment period. Those who started prophylaxis in the adolescent years had a much more rapid rise in treatment lapses than did those who started in the early school years, no matter how long they had been taking penicillin.

Activity and Bed Rest

Strict bed rest may be imposed upon the child with rheumatic fever because of the possibility of rheumatic heart disease. Although Massell (3) states the incidence of carditis in rheumatic fever to be around 50 percent, the exact incidence, including subclinical carditis, is unknown. Decisions about length of treatment and criteria for rest and activity vary considerably from patient to patient and often from doctor to doctor. Each nurse needs to be sufficiently familiar with these criteria to raise questions with the physician responsible for her patient's care when a plan is not well understood by the patient or family. In planning the daily care for these children, the nurse's role is an important one whether she is acting in place of a mother round the clock, as with the hospitalized child, or whether, as a public health nurse, she is helping the mother of a homebound child plan his daily activity within the family setting.

Some children with polyarthritis have joints so painful they can endure only the most gentle handling. During such a phase of acute illness, hospitalization may be required because 24-hour nursing care is indicated. Should such a youngster be cared for in the home, the mother

needs some regular nursing assistance and relief, in addition to the instruction, demonstration, and supervision provided by the public health nurse.

In the hospital, such aids as foot rests, bed cradles, and other devices for proper positioning, will be readily available. At home, the necessary devices may be improvised or borrowed from a "loan closet" maintained in many communities by the public health nursing agency or by one of the service organizations. For example, the dyspneic child who is unable to lie back against the pillow may be helped by an overbed table or some cushioned support which enables him to lean forward in order to rest.

For many years bed rest and reduced activity have been part of the treatment of heart disease. More recently the dangers accompanying prolonged bed rest, as pointed out by Asher (4), have been recognized and bed rest during both the acute and convalescent periods of most medical and surgical conditions has been shortened.

The medical and nursing professions are gradually accepting the concept that bed rest and restricted activity can be a mixed blessing. Difficulties inherent in keeping a child in bed or in limiting his natural activity are well known. Few parents and children have not experienced the frustration and conflict arising out of a physician's recommendation for bed rest during convalescence from common colds or childhood diseases. Consider how these unpleasant effects must be multiplied by rheumatic fever with its long convalescence and problems of preventing carditis.

The nurse's understanding and realistic explanation that bed rest and activity restriction are preventive measures as vital as antistreptococcal prophylaxis is of great importance. A child who knows he is a member of the treatment

team, with his parents, physician, and nurse is more likely to accept recommendations than one who feels he is merely the object of adult discipline.

Summary

Nurses may make important contributions toward the rehabilitation of the child with rheumatic fever or rheumatic heart disease. They can advise both child and family regarding prevention of recurrence; they can help school nurses and teachers to understand what heart disease in childhood means; they can use school health services in finding and following cases; they can devise ways of keeping effective records and referral forms; they can work closely with community health and welfare agencies and professional personnel; they can keep current with the latest medical information; they can serve as links in the chain of events from the time of diagnosis until the child reaches maturity and assumes his rightful place as an individual, a family member, and a citizen in the community.

The happiness and dignity of the individual patient may depend on the willingness and ability of the nurse to accept the responsibility implied in this newer concept of patient care.

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